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ABSTRACT

Forces providing impetus for compensatory early education--namely, the civil rights movement and the shattering of the predeterministic credo of the fixed intelligence quotient--have also worked in behalf of the handicapped. But for the handicapped one additional force has also been in operation: parents and citizens organized into political action groups. As a result of parent efforts, several Congresses enacted legislation that has altered the lives of many young children and their families. Important legislation focusing specifically on young children includes Public Laws 88-164, 89-750, 90-538, 91-230, 91-517, 92-924, 93-247, and 94-142. Each of these laws has made an important contribution to the education of the handicapped. Still, even in the best of times, less than half of the children needing special services have been helped. Crucial issues bearing on handicapped children and early intervention remain to be addressed: (1) identifying types of children most responsive to early intervention programs, (2) determining which of the many early intervention programs and curriculum models is most effective, (3) determining what measures provide the most important indices of change, (4) identifying cost-effective service delivery models, and (5) deciding the best form of family involvement. Issues such as these are unlikely to be adequately addressed by "seat-of-the-pants" attempts at improvement. (RH)

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PROGRAMS FOR THE YOUNG HANDICAPPED CHILD: A POLICY PERSPECTIVE

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EARLY INTERVENTION AND THE HANDICAPPED CHILD:
A POLICY PERSPECTIVE

K. EILEEN ALLEN

During the past two decades, young children and their special needs have been the focus of several major shifts (and rifts, I might add) in social policy. Several forces may be seen as having given impetus to these shifts. One is the Civil Rights movement and the gradual enforcement of school desegregation. It was this exposure of grievously inequitable and even inhumane school situations throughout the country that prompted "considerable soul-searching among the guilt-ridden haves and havenots" (Meier, 1974)--soul-searching that led at least to some of the changes that have come about over the past 20 years.

A second force was the findings on the efficacy of early intervention as documented by Skeels and Dye (1939), Skeels (1966), Rheingold (1956), and Kirk (1958). Almost concurrently came the work of J. McV. Hunt (1961), and Bloom (1964), shattering the mystique of predeterminism and the fixed I.Q. The outcome of all of this was the compensatory education movement of the 1960s, culminating as we all know in Head Start. Much could be said about Head Start because, for the first time in history, large numbers of young children and their families were involved in a generally popular program that nevertheless was, and continues to be on some fronts, socially and politically controversial. For our purposes here today, however, let it be said that what Head Start did for developmental psychology and Early Childhood Education was to provide a vast arena of practical experiences and settings for "systematizing and understanding the enrichment/intervention paradigm" and in retrospect, providing "a scenario we can examine to get a more precise view of what efficacy within

an early intervention framework means" (Salkind, in press).

Running almost parallel to the compensatory early education movement for the educationally deprived children was a similar movement, that of providing early intervention programs for young handicapped infants and children. It is these programs, and particularly those that have federal authorization and funding that will be the focus of this paper.

Just as Head Start had been described as "an idea whose time had come" (Zigler and Anderson, 1979), so also was early intervention with the handicapped an idea whose time had come. The same forces were at work on behalf of the handicapped as had been mentioned earlier in providing impetus for compensatory early education--the Civil Rights movement and the shattering of the predeterministic credo; but, for the handicapped, there was yet one more powerful element--aroused parents and citizens who had formed into highly visible political action groups. Most notable among these was the National Association for Retarded Children (NARC), later renamed the National Association for Retarded Citizens. These groups lobbied long and vigorously on behalf of the handicapped and as a result of these efforts (at least in part as a result of these efforts) we do see the next several Congresses enacting legislation that has dramatically altered the lives of many (though still not enough) young children and their families. Those laws that focus specifically on young children will be touched upon briefly as follows.

When President Kennedy (with his keen sympathy for the handicapped) came into office, the special interest groups began to agitate even more vigorously in the Congress for legislation to benefit the mentally retarded. The culmination of these efforts was the enactment of P.L. 88-164 entitled Facilities for the Mentally Retarded. The passage of this bill is viewed as a monumental landmark for the handicapped. It signalled the beginning

of the federal government's participation in service, training, and research activities in the field of mental retardation (and related handicapping conditions) in specially built and specially funded University Affiliated Facilities (UAF's).

The UAF's, now 36 in number, are multi- or interdisciplinary in principle and practice and are located strategically throughout the country. It is in many of these centers that the "whole child" concept as it relates to developmental irregularities in young children is being investigated. As an aside, it might be noted that it is in these centers, too, where evidence is accumulating as to the importance of an interdisciplinary team headed by a case manager (not necessarily a medical person) in effectively intervening in the developmental problems of young children (Holm 1978). A second important finding coming out of many of the UAF's research programs has to do with the need for parent partnership in designing and carrying out their handicapped child's program. Both of these findings we will see formalized in subsequent legislation that I will touch upon later in this paper.

P.L. 89-750

In 1966, Congress mandated the United States Office of Education to establish the Bureau of Education for the Handicapped. This bureau, up until it was reduced to the Office of Special Education a couple of years ago, became the agent (and most effectively, I might add) for all jurisdiction of programs for the handicapped, including a variety of early intervention activities.

P.L. 90-538

The next major piece of legislation, and the first to focus exclusively on young handicapped children, was P.L. 90-538, the Handicapped Children's Early Education Assistance Act. Signed into law in 1968, this statute

provides federal funds for the education of young handicapped children in experimental demonstration centers. Popularly referred to as the "First Chance Network", these programs (eventually numbering nearly three hundred) place heavy emphasis on innovative programming, parent participation, and the systematic collection of evaluative data.

P.L. 91-230 and P.L. 91-517

The ninety-first Congress also passed legislation (several pieces, in fact) that benefited handicapped children; the two that have most relevance to young children will be mentioned here. One was P.L. 91-230 which had to do with the integration of handicapped children into regular preschool and day care programs. In addition, this law also provided for the establishment of model preschool programs, several of which have been validated as demonstration and training sites. P.L. 91-517, the Developmental Disabilities Act was also enacted in this Congress. This bill expanded the range of disorders that could be included under the rubric of handicapped to include the epileptic, cerebral palsied and other neurologically impaired children.

P.L. 92-924

Head Start, though always having an "Open Door" policy for all children, was mandated specifically in 1972 to serve handicapped children. P.L. 92-924, an amendment to the Head Start portion of the Economic Opportunities Act, requires that no less than 10 per cent of Head Start funds be used to serve handicapped children in an integrated setting. The law also calls for special programming for each handicapped child as prescribed by a multidisciplinary child study team. In 1974, Congress redefined the ruling to ensure that severely handicapped children were served; to be included were the deaf and hearing impaired, blind and visually limited, mentally retarded, seriously emotionally disturbed, and the orthopedically crippled

and otherwise health-impaired.

P.L. 93-247

Even the ninety-third Congress passed an important piece of legislation on behalf of children. This was the Child Abuse and Treatment Act, P.L. 93-247, signed into law by President Nixon. This law is of particular importance in early intervention efforts in that many handicapped children have histories of abuse by adults.

P.L. 94-142

The final piece of legislation to be mentioned is P.L. 94-142, the Education for All Handicapped Children Act. It was President Ford who signed this law in 1975, a law that is seen as the second piece of landmark legislation on behalf of the handicapped. P.L. 94-142 is designed to increase considerable federal support for a free and appropriate education for handicapped children as a part of their constitutional right, (just as it is the right of all other children). In addition, the law offers unprecedented incentives for state and local school districts to provide early intervention services for young handicapped children in preschool settings. While the law was designed to make federal money available for education of the handicapped, it also spells out other significant changes related to improvement of the educational scene for handicapped children and their families. These include:

NONDISCRIMINATORY EVALUATION OF CHILDREN--Testing and evaluation materials must be used that do not discriminate on the basis of the child's culture or language; results of a single test cannot be the sole basis for a decision regarding placement or change in a child's status.

INDIVIDUALIZED EDUCATION PROGRAM (IEP)--Every child must be provided a written IEP, updated periodically, and based upon the recommendations of a

multidisciplinary child study team in consultation with the child's parents.

DUE PROCESS--To insure the child's rights there must be written notice before changes are made in the child's educational status; parents or guardian are entitled to a hearing and an appeal if they disagree with the school's proposed plan for the child.

LEAST RESTRICTIVE ENVIRONMENT (THE MAINSTREAMING CONCEPT)--Education must be provided in a setting that is least restrictive of the child's development; as much as possible, this should be in a regular school or day care setting.

Each of the foregoing mandates is a significant breakthrough for handicapped children and their families; it takes no clairvoyance to see why P.L. 94-142 is often called the "Bill of Rights for Handicapped Children".

Having finished this brief review of legislation related to handicapped preschool-age children it is a temptation to begin a diatribe aimed at the current administration for its repeated attempts to undermine the hard-won gains that are represented in these laws, and to rail against the recurring efforts to dismantle or render the programs impotent by wrapping them into block grants, while simultaneously proposing massive deregulating -- all of which almost guarantees that whole populations of children with special needs will go unserved. However, the intent of this paper was not to detail the impact of the Reagan Administration's cuts on programs for the handicapped,[1] but rather to describe social policy and the early intervention issue as it related to young children who are handicapped or at risk for handicapping conditions. The more forward-looking issue is where do we go from here in terms of the long-term economic picture, social

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1 A companion paper is available in which these destructive cuts are sketched out in the context of the specific pieces of legislation.

policy, and decision-making as these relate to early intervention? After all, even in the best of times, we have never served even half of the young children in need of special services. So let us turn now and look very briefly at a few of the more crucial issues that will have bearing on handicapped children and early intervention.

Heading the list most surely, at least for applied developmental psychologists and early childhood educators, is the question of evaluation, for this issue underlies almost all other questions and their potential answers. Admittedly, there is a fairly convincing literature (though most of it of the post hoc variety) attesting the efficacy of early intervention with low income, educationally disadvantaged children (Lazar, 1979). The data, however, are less robust in the area of early intervention with the handicapped (Garland, Stone, Swanson, and Woodruff, 1981). It is beginning to accumulate, however, thanks to the concentrated efforts of the directors of many of the programs described earlier. Nevertheless, there are still many issues at stake--issues that often apply to early intervention programs for normally developing children as well as to those for handicapped children. Let us turn now and set some of these questions out for conscious inspection.

WHICH CHILDREN?

Which types of children are most responsive to early intervention programs? If our data were to tell us, for example, that certain kinds of children respond better than others to early intervention, do we invoke some kind of a selection process? What kind? Are we perhaps going to have to consider triage (Haines, 1982), focusing our intervention efforts on the infants and children in the "middle"--those children who will display the greatest gains from having our limited resources concentrated upon them--rather than the children at the upper end of the atypical continuum (the

"walking wounded" in the triage paradigm) who will get through, somehow, or those at the other extreme for whom the probability is very low that they would ever approach even minimal self-sufficiency, let alone recovery, in spite of our best and most intensive long-term efforts?

WHICH PROGRAM MODELS?

Which of the many early intervention program and curriculum models is most effective? Is the mainstreaming model appropriate for all children, handicapped and nonhandicapped? Are there certain models more effective than others for handicapped and developmentally delayed children, or as Allen (1981) asserts, can any sound, theoretically based early intervention model be adapted to children of every type, regardless of where they place on the developmental continuum?

WHAT TYPE OF MEASUREMENT?

What measures provide the most important indices of change? Should we be revamping our efficacy evaluation procedures to routinely encompass, as Salkind (in press) argues, both a substantive perspective--that is how intervention efforts affect the child's growth and development--and a policy perspective related to the no-less-important results from early intervention programs such as benefit-cost ratios and cost-effective outcomes?

ARE THERE COST-EFFECTIVE SERVICE DELIVERY MODELS?

Are we on the right track with our "tried and true" service delivery models? No one argues, for example, that young children are complex entities who require, when developmental problems arise, the collaboration of several disciplines. But what is the best framework for providing multidisciplinary services? Is the answer to be found in the demographic characteristics of the situation? In large urban areas do we concentrate on interdisciplinary centers such as those provided by the UAF's while in small towns and rural areas we look at the kind of interagency delivery

systems that Peterson (in press) proposes?

WHAT KIND OF PARENT INVOLVEMENT?

What is the best form of family involvement in light of substantial evidence that no early intervention program is likely to be effective without it (Bronfenbrenner, 1974)? What are the specifics of the family's impact on the handicapped child on family functioning? And, as Garwood asks (1981), in what ways can parents best be involved in order to broaden the transactional (and generalizational) context of early intervention efforts?

These are but a few of the many questions that must be addressed as we move forward in defending, refining, and expanding our belief in the efficacy of early intervention with children with special needs, be they handicapped or nonhandicapped. But, in addition to having to face such complex issues, it seems likely that we in academia may have to learn also to live with changing support patterns over the next several years. Gone, I fear, are the halcyon days that John Meier, former Director of the Office of Child Development, (OCD, now ACYF) wrote about with such optimism in 1976: "The growing attention and burgeoning federal and state legislation to provide needed services for all citizens, including educational programs for children from birth, whether they be normal or abnormal, augur well for more extensive and intensive programmatic efforts on behalf of all children, including the most promising as well as the most vulnerable" (p. 31). It should be noted, however, that this period of "burgeoning legislation" had also, by Meier's own admission, been a "decade of undulating and incoherent legislation" (regardless of how orderly it all appears when briefed out as I have done on the pages which I have given you). Perhaps it is this very legislative incoherence that has contributed in no small part to today's policy scene being so different from that described

by Meier.

Gallagher (1981), it would appear, is well-tuned to today's social/political scene as far as policy is concerned, when he says, "Currently there is a growing realization that attempts to improve American Society can no longer be based on a "seat-of-the-pants", largely uncorrelated and uncontrolled set of innovations. Such strategy yields uncontrolled budgets, disappointment, and despair." And Jim Gallagher ought to know! He has interrupted his career twice at Chapel Hill to serve our government, first as Chief of the Bureau for Education of the Handicapped, and later as Deputy Assistant Secretary for Planning, Research, and Evaluation in the U.S. Office of Education. His cautionary words would seem to provide a good closing for this paper. They are sobering but nonetheless realistic for those of us who would improve the lives of children and families through social policy reform based upon developmental research.

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